

**Pay for Performance
Mini-Summit Notes
January 18, 2008**

What is important to you?

- As a parent, my daughter has a job she likes, choices!
- As a parent, quality of life, health, happiness are most important
- As a brother, content & happy now; staff continuity & flexibility
- As a mother, son works at a Supermarket- is happy...afraid to lose this
- As a mother, she makes her own decisions, has exceptional staff, lives on her own, our quality of life is good, she does not have a "borrowed life"
- As a mother, daughter does things meaningful to her that are connected to her interests & preferences...many have to compromise however
- Individually tailored outcomes...outcomes vary person-to-person, e.g. paying job may not be for everyone, some outcomes matter more for some than others
- Outcomes we measure can translate into individualized goals
- Honoring what's good in the current system...not moving forward too quickly with reform
- Relationships are the most important...preserving the relationships in transition (i.e. from student life to adult life)
- As a person with a disability, that we notice what people do *well*
- Bigger is NOT better
- Recognizing the Direct Support Professionals
- As a parent, continue to choose the agency that supports our daughter
- People get not only what they *need*, but what they *want*
- Societies understanding of "disability"
- Quality of life, such as enjoyable and meaningful activities, people with whom one has a mutual caring, a comfortable and happy place to live, and that persons have the ability to define for themselves the quality of their life
- Continuity of care is very important
- That my child continues to be happy and safe
- Important is the ability to do what is meaningful
- Important is the training and provision of information to people transitioning in – provide knowledge about what opportunities exist – help to navigate the system as there are major issues in transitioning from an entitlement system to an eligibility system. Some of the important elements of transition are:
 - Communication
 - Training and information
 - Resources
 - Options
 - Use of the ISP as a tool to assure that needs and wants are met
 - Relationships in the community re critical – can help some people through the transition, e.g., continuation of the mentor function

Is it currently in the system & is it delivered well?

- Individual results
- Flexibility
- Organization (PAL) that already measures family/loved one satisfaction
- Choice in all aspects of life is now available and want to maintain that
- There is now a good continuum of care in the system, with flexibility for persons
- Many transitioning families have the ability to make meaningful choices, but many do not
 - The choices in transition are diminishing
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What new and/or better results would you like?

- All individual choices are honored...and smoother navigation of the system for families
- Use ISP better- develop more personalized plans
- Understand ranges of capacity...success is different for everyone
- Employment...story of middle age man with track record of competitive employment unable to secure a job in RI
- Amount of positions held in municipalities by people with disabilities
- Equalizing access to information for all families & individuals
- Ways to find people work...lots of people waiting to work
- Better job with supporting meaningful relationships
- Outcomes for the Governor and general assembly

What is the best way to assure those results?

- Preserve diversity
- Take the time to do this properly!
- Measure family/loved ones satisfaction
- Outcomes equal for people of varying level of ability
- Sustaining relationships throughout all transitions and supports
- Should agency results be a measure of individual satisfaction? (and vice versa?)...creating a system that allows for difference
- Any kind of cuts/consolidation will hurt
- “Wants” are recognized as well as basic “need”
- Allows for forward three steps, back two...this is how we all grow
- Measure societies understanding of people with disabilities...why their support is important
- Incentives for companies or government to employ people with disabilities
- Need to resources to address the reports of outcome achievement
- Input correlates with outcome
- Accurate data
- Acknowledge and compensate the Direct Support staff

- Individually tailored outcomes
- Assess: Are this person's goals being achieved?
- Agencies keep the distinction between agency performance measures and individual satisfaction & goals
- In setting outcomes...look at three populations (sets of outcomes for each); 1) Older folks (maybe lived a Ladd), 2) In-between 3) 16-21 year olds
- Staff stability is critical for continuity of care – worry that budget cut will affect that stability
- When design the outcome measures, need to remember that outcomes will not be the same for all persons...some are more gifted than others; some require much support to participate in the community...we have a large number of persons with multiple problems. Need to remember these points
 - Nothing works for everybody
 - Need to have flexibility in measuring outcomes
 - The criteria must be very specific
 - Do not make the assumption that what is important to one person, or one set of persons, is important to others
 - Outcomes must be individually tailored to each person
- The ISP process can be measured, e.g., have goals been met or not
- Re: the RFP: need to look globally; need enough measures to capture everyone, e.g., employment may be best for some... for others, volunteer work may be best
 - Most important is that individual outcomes, as opposed to system outcomes, are attained
- Re: employment, the notion of job sharing, the breaking up of jobs
 - When determining outcomes, need to consider ranges of individual capacity
- Need awareness of the difficulties in transition and the need to focus on persons getting through (the issue of waiting)
- Need to remember the three distinct populations
 - Persons from Ladd, many with medical issues
 - All the people in the set age 21 – Ladd
 - The 16-21 year-olds
 - So, need different sets of outcomes based on where people are in life
- Need better identification of employable persons, and finding those employable persons jobs

PARKING LOT

(ideas, concerns, questions that fell outside of this conversation)

- In transition to adult services...there needs to be better Training & Information, Resources, Options
- Sustaining what's important to people in transitions
- How will all this information (gathered today) be used???
- How do we (our system) fit into everyone else's agenda???
- Establish- how many people with a disability fill a municipal position?

- Slow down this process...don't compromise what's good.
- Would like to set some outcomes for the government and leadership of Rhode Island!
- Consolidation will hurt quality of service